alzheimer's \bigcap association

THE BRAINS BEHIND SAVING YOURS:

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Representing the Alzheimer's Association, Montana Chapter and the Montana Alzheimer's and Dementia State Work Group – comprised of over 70 concerned individuals and organizations from throughout the state.

There is so much to consider as we look at the growing epidemic that is Alzheimer's and dementia in our state. First – where we are today.

Scope of Crisis

Alzheimer's disease is the nation's largest under-recognized public health crisis. An estimated 5.8 million Americans are living with Alzheimer's dementia today, and by 2050 the number of people with Alzheimer's dementia may grow to nearly 14 million. It is the sixth-leading cause of death in America. In Montana, over 21,000 people are living with Alzheimer's – hundreds more are living with a related dementia. Another 50,000 family members are providing their care. By 2025, over 27,000 people will be affected. Those numbers grow unabated as we currently have no way to stop, slow or prevent Alzheimer's – not yet.

Age is the greatest risk factor for the disease. The large majority of people exhibit symptoms at age 65 and older. By 2030, nearly a third of our state's population will in that category. One in three seniors dies with Alzheimer's or another dementia.

We already feel the financial impact. Montana Medicaid costs for people with Alzheimer's will reach \$157 million in 2019 and is estimated to increase nearly 28% in just the next 6 years. A study published in *The New England Journal of Medicine* confirms that Alzheimer's is the nation's most expensive disease.

And not just for the individuals with the disease. More than 50,000 Montanans are serving as caregivers for family members and friends living with dementia. In 2018 they devoted 57 million hours to this care, valued at \$723 million. Their health and well-being suffer – with caregivers experiencing \$37 million in health costs last year. The implications are expansive – six in ten caregivers are employed – yet nearly 20% end up cutting back on their hours, quitting working altogether or retiring early. The caregiver burden cannot be overstated; nearly one in seven caregivers will predecease the person for whom they are caring.

We are not here to ask you to fix this. It will take all us working together. Our vision is bold and necessarily so.

We envision heightened community and medical provider awareness that will lead to a dramatic increase in the accurate and timely diagnosis of people living with dementia. As a result, we could see a significant increase in the number of people with dementia and their caregivers who receive timely affordable, high-quality care and support. This is not currently the case – as most care is crisis driven.

We see increased and continued dementia training for direct care workers and allied providers — to improve person-centered care and to increase employee retention and satisfaction. In doing so, care workers will be better able to anticipate and mitigate the potential behavioral outcomes that result in chemical or physical restraints or escalated, more costly and inappropriate interventions.

We envision centers of excellence in our state to expand and advance effective Alzheimer's interventions. We seek support for public health departments to promote cognitive health, risk reduction, early detection and diagnosis, and support. We need to increase collection, analysis and timely reporting of data on cognitive decline and caregiving to inform future public health actions.

It will require us working together to increase awareness and implement a proactive multidimensional response leading to better quality of life and quality of care. Thank you for your dedication and service. And thank you for your consideration of all those who need your leadership to help address this public health crisis.



NUMBER OF DEATHS FROM ALZHEIMER'S DISEASE (2017)

285

Death certificates for those with Alzheimer's often list acute conditions such as pneumonia as the primary cause of death. As a result, people with Alzheimer's who die due to these acute conditions may not be counted among the number of people who die from Alzheimer's although it may have been the causative factor.



580

of people in hospice with a primary diagnosis of dementia

13%

of people in hospice have a primary diagnosis of dementia



\$17,455

per capita Medicare spending on people with dementia (in 2018 dollars)



HOSPITALS (2015)

1,230

of emergency department visits per 1,000 people with dementia

16.3%

dementia patient hospital readmission rate



MEDICAID

\$157 MILLION

Medicaid costs of caring for people with Alzheimer's (2019)

27.7% change in costs from 2019 to 2025

65 + NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

* Totals may not add due to rounding

Year 2019	65-74 3,300	75-84 8,900	85+ 8,800	TOTAL 21,000

Estimated percentage change





For more information, view the 2019 Alzheimer's Disease Facts and Figures report at alz.org/facts.



CAREGIVING (2018)

50,000 Number of Caregivers

57,000,000 Total Hours of Unpaid Care

\$723,000,000 Total Value of Unpaid Care

\$37,000,000 Higher Health Costs of Caregivers



US STATISTICS

Over 5 million

Americans are living with Alzheimer's, and nearly 14 million will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total \$290 billion in 2018,

\$290 billion in 2018, increasing to \$1.1 trillion (in today's dollars) by mid-century. Nearly one in every three seniors who dies each

year has Alzheimer's or another dementia.

THE IMPACT OF **ALZHEIMER'S ON** THE WORKPLACE

Americans provide unpaid care for people living with Alzheimer's or other dementias.

were employed in the past year.

These individuals worked an average of

per week while caregiving.

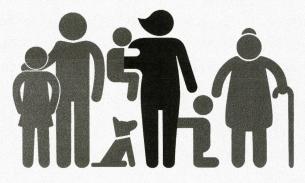
OF EMPLOYED CAREGIVERS HAD TO GO IN TO WORK LATE, LEAVE EARLY OR TAKE TIME OFF DUE TO CAREGIVING DEMANDS.



18% of caregivers went from full-time to part-time or cut back hours. line percent

of caregivers gave up working entirely.

Six percer retired early.



of caregivers are in the "sandwich generation" — meaning they care for an aging parent and children under 18.

HOME IS PROVIDED BY FAMILY MEMBERS, FRIENDS OR OTHER UNPAID CAREGIVERS.





/oman

are more likely than men to perform caregiving tasks, a role which often competes with other responsibilities such as employment.

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Visit alz.org for caregiver support, information and resources.

Sources: 2018 Alzheimer's Disease Facts and Figures Research Report: Dementia Caregiving in the U.S.



FACTSHEET

JUNE 2019

alzimpaoi.org

Dementia Training for Direct Care Workers

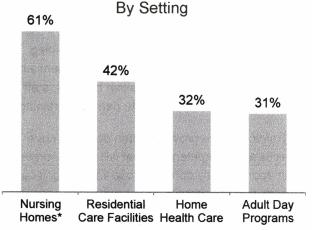
Those with Alzheimer's are high users of long-term care services.

- At the age of 80, 75 percent of people with Alzheimer's are expected to be admitted to a nursing home, compared with just 4 percent of the general population.
- People living with Alzheimer's are nearly four times as likely to need skilled nursing facility care and over twice as likely to require home health care as individuals without the condition.
- More than 60 percent of seniors living in a nursing home have moderate or severe cognitive impairment. Among those in residential care settings, 42 percent have Alzheimer's or another dementia.

Individuals with Alzheimer's have needs that often make care delivery challenging and more demanding.

- More than 95 percent of individuals with dementia have at least one other chronic condition. Caring for someone with multiple chronic conditions especially when that includes dementia significantly complicates the care needed.
- As the disease progresses, individuals are unable to complete activities of daily living (such as eating, dressing, and bathing) without assistance.
- Over time, people with Alzheimer's will lose the ability to use words and may communicate their needs through behavior, which presents added challenges for care workers.

Percent of Individuals with Alzheimer's



*Percentage with moderate or severe cognitive impairment

What Can States Do?

- Require a minimum of six to eight hours of evidence-based dementia training for all those who serve individuals with dementia.
- Ensure continuing education to reinforce best practices in the care of those with dementia.
- Implement a culturally-competent curriculum that incorporates principles of person-centered care.
- Allow portability of completed dementia care training across employment settings.
- Ensure trainers meet minimum requirements to qualify as instructors of a dementia curriculum.
- Designate a state agency to monitor dementia training programs, evaluate their effectiveness, and ensure compliance with state dementia training requirements.

Care workers often do not have sufficient dementia-specific knowledge to effectively support those with Alzheimer's and other dementias.

- Certified nursing assistants and home health aides receive at least 75 hours of required training. But, Alzheimer's and dementia care is only one of 40 required topics that must be covered in this time frame.
- While reviews have shown that staff training programs to improve the quality of dementia care in nursing homes have positive benefits, staff are unlikely to receive adequate dementia training.
- Training that is provided often does not cover the skills and competencies that will equip workers to appropriately care for those with a significant cognitive impairment.
- Even in states with dementia-specific training requirements, many of those policies are out of date, cover only a subset of workers, lack competency standards, and have inadequate enforcement mechanisms.

Dementia training of those involved in the delivery of care can improve the quality of care and experiences for individuals with Alzheimer's and other dementias.

- A cornerstone of providing quality dementia care is to ensure that all professional care staff involved in the delivery of care to people with dementia receive dementia-specific training.
- Dementia training should ensure that care workers have the ability to:
 - o Provide person-centered dementia care
 - Communicate with individuals with Alzheimer's
 - Address behavioral symptoms, including alternatives to physical and chemical restraints
 - Address specific aspects of safety, such as wandering.
- Periodic continuing education is also needed to ensure that care workers have the latest information on best practices in the care of those with dementia.

Direct Care Workers: Who Should Receive Training?

Direct Service Staff

An employee whose work involves extensive contact with participants or residents. These staff members may have different titles and may include registered nurses, licensed practical nurses, licensed vocational nurses, nurse practitioners, certified nurse aides, nursing assistants, physician assistants, home health or personal care aides, activities directors, feeding assistants, social workers, dietary staff, respite care providers, adult day care providers, and all occupational, physical, and speech therapy staff.

Administrative Staff

A senior manager of a facility or program, including administrators and managerial staff that supervise direct service staff.

Additional Staff

Those who have incidental contact with residents or program participants on a recurring basis. That includes people include housekeeping, front desk, maintenance, or other administrative staff, as well as other individuals who have such incidental contact.